

Revised Application 11/4/2020 4:33 PM

**Yale University President's Public Service Fellowship**  
Summer 2021

**Proposal for Fellow working remotely for organization**

- **Organization:** Sickle Cell Disease Association of America Southern CT
- **Full street address of organization:** 1389 Chapel Street, New Haven, CT 06511
- **Website:** [www.michelleshousect.org](http://www.michelleshousect.org)
- **Name and title of person who will be the Fellow's direct supervisor:** James Rawlings, R.PH, MPH
- **Phone number and e-mail address of proposed direct supervisor:** 203-859-5355 (Office); 203-215-1521 (Cell); [jamesrawlingsscdaa.sc@gmail.com](mailto:jamesrawlingsscdaa.sc@gmail.com)
- **Placement dates:** 11 weeks between June 1<sup>st</sup> and August 13<sup>th</sup>
- **Are placement dates flexible?** Yes. Are you able to accommodate a Fellow working in a different time zone? Possibly
- **Proposed 37.5 hour per week work schedule:** 9am – 5pm
- **Organization description:**

In pursuit of systemic change, SCDAAC/ Michelle's House embraces prevention strategies to enhance the quality of life and well-being of the Sickle Cell Disease (SCD) community and related sequelae and to provide individuals and families with critical education and access to direct and support services.

The population served is the sickle cell community locally and regionally in that every program we initiate to the extent possible is framed in such a way that our models and interventions are portable and replicable to add to the armamentarium of resources to

enhance the quality of life of the Sickle Cell Community (SCC) inclusive of significant prevention initiatives.

Statistically the population served are the 1 in ten African Americans and 1 in 25 Hispanics and other racial groups to a lesser extent who carry the SCT and equally important those living with SCD in Southern CT.

- **Write a 1-2 sentence summary of the work that the Fellow would be conducting:**

The Sickle Cell Program supports clients with this rare genetic disease that negatively impacts the quality of life of this very vulnerable Sickle Cell Community (SCC).

Unfortunately, there has never been a comprehensive report of such undertaking. The fellow will assist in the production of an inclusive report that documents the experiences of those impacted, across the diversity of challenges of the SCC. This report will serve to inform with recommendations all stakeholders of the strengths and failures the SCC continues to endure.

- **Write a more complete description of the specific project you propose and list the duties/outcomes expected of the Fellow.**

Sickle Cell Disease which is categorized as a rare genetic disease impacts disproportionately African Americans and to a lesser extent the Hispanic community either directly or indirectly. This genetic disease was discovered over 100 years ago and there is still no cure in sight only palliative care. Further an equally significant there is no statewide report on the status of Sickle Cell Disease in CT and therefore little or no community understanding of the impact of this disease. Also, very importantly there is no statewide comprehensive plan that includes Sickle Cell clients and community involvement that addresses the socio-economic variables and determinants so detrimental to the Sickle Cell community.

Some of the manifestations and variables of the disease to be explored and documented that significantly negatively impact those with the disease and those who carry the trait are:

- The clients with Sickle Cell Disease (SCD) have very frequent hospitalizations due to what is called sickle cell crisis. According to outdated CT hospital data those with SCD average 4-6 admissions annually. Further 20% have average per individual admission rates exceeding 12 admissions annually.
- Similar outdated data also reports that babies born on CT tracked by CT Newborn Screen g program has grown by 17% over the most recently reported 5-year time period.

- Youth who transition from pediatrics to adults is very uneven in CT and the impact on their academic success, outcomes and goals related to successful transactions are not well understood studied and or shared.
  - SCD is a genetic disease and there are many individuals who carry the Sickle Cell Trait (SCT). In fact, one in ten or one in 12 AA carry the trait yet we find that too few understand their trait status and more importantly clearly understand the risk they pose to future generations. There is a critical need to understand the risk they potentially pose unknowingly to future generations of newborns being born with SCD and to a lesser degree with SCT. Our goal is to reduce the number of newborns with SCD were the parents maybe unaware of their trait status and or unaware of the genetic implications.
  - Another significant issue not well documented is the impact on the educational and academic challenges and achievements of youth with SCD. Some studies have documented the rate of academic failure or recidivism annually is as high as 40%. Many communities are unaware of this significant issue and many youth within most school systems are unaware once again of the harm imposed on these youth who live with SCD. Some studies have documented that up to 60% of youth with SCD report that the disease negatively impacts on their academic success.
  - Further there is little understanding of the socio-economic status of most individuals and families impacted and how this status further diminishes their quality of life compared to the general community.
- **List specific skills/experience required for this work: Intellectual curiosity and basic literature research skills**

Intellectual curiosity and basic literature research skills

- **Equipment/resources you will provide to help Fellow conduct work:**

N/A

- **Briefly describe the work that Yale PPSF Fellows have done with your organization in the past and present. If you have not worked with Yale Fellows, describe any work that Yale students have done with your organization.**

2018 PPSF developed a pilot awareness program that has now matured into one of our key new programs. The initiative was modeled by our PPSF in corporation with the New Haven Health Department. The objective of the awareness program is to introduce

prevention into our campaign to combat Sickle Cell Disease and the continued expansion and growth of babies born in CT with SCD and with the SCT.

2020 PPSF - Worked on two critical new initiatives (1) Building a tutorial program for students with Sickle Cell Disease; (2) Working with the State DPH to obtain valuable data that could be used to improve many aspects of the quality of life of the Sickle Cell community inclusive of improving and addressing the excessive M@M that is so preservative and unattended.